Sexologies (2008) 17, 258—264

Disponible en ligne sur www.sciencedirect.com

ScienceDirect

journal homepage: http://france.elsevier.com/direct/sexol

ORIGINAL ARTICLE/ARTICLE ORIGINAL

Medical care for gender variant young people: Dealing with the practical problems

Soins médicaux pour les jeunes ayant des troubles d'identité de genre : traiter les problèmes pratiques

Cuidados médicos para jóvenes con problemas de identidad de género: Gestión de los problemas prácticos

B.W.D. Reed[a,*], P.T. Cohen-Kettenis (Ph.D)[b], T. Reed[a], N. Spack (MD)[c]

[a] *Gender Identity Research and Education Society (GIRES), Melverley, The Warren, Ashtead, Surrey, KT21 2SP, England, UK*
[b] *Department of Medical Psychology, VU University Medical Center, Amsterdam, The Netherlands*
[c] *Endocrine Division, Children's Hospital, Boston, Massachusetts, USA*

Available online 23 September 2008

KEYWORDS
Gender identity;
Gender role;
Transgender;
Psychological assessment;
Endocrine intervention;
Paediatrician

Summary Although many clinicians, perhaps unknowingly, have young patients who experience gender variance, they will rarely encounter a case where the condition appears profound and persistent. Strong social pressures, within the family and at school, usually inhibit any revelation of gender variance. If families do identify the gender variance and seek medical help, the prudent response would be to refer the youngster to a specialised paediatric service that offers multidisciplinary care, provided by experienced mental health professionals and endocrinologists, in accordance with the internationally recognised standards of care. However, in many countries, there is no such service or the service available follows an approach that is unacceptable to the young people and their families. In that situation, the clinician faces a range of practical problems. At the prepubertal stage, even the most experienced mental health professionals cannot predict the likely persistence of the condition. However, at the onset of puberty, a reliable prognosis is often possible. Then, the clinical response in many advanced countries is to suspend puberty. That relieves the stress caused by bodily changes that conflict with the young person's gender identity. It also provides patients and clinicians with more time in which

* Corresponding author.
E-mail addresses: admin@gires.org.uk, bernardgi@aol.com (B.W.D. Reed), PT.Cohen-Kettenis@vumc.nl (P.T. Cohen-Kettenis), terry2reed@aol.com (T. Reed), norman.spack@childrens.harvard.edu (N. Spack).

1158-1360/$ – see front matter
doi:10.1016/j.sexol.2008.08.004

to confirm the prognosis, following which the alignment of the body with the gender identity can commence. Initially, this is achieved by the administration of cross-sex hormones. Ultimately, usually in adulthood, surgery is provided to complete the physical transformation. The clinician contemplating such a treatment pathway for an adolescent, needs to be aware of: the legal and ethical issues that relate to medical care for this patient group; the ongoing educational and support needs of the young person's family and school; the resourcefulness demonstrated by some parents, for instance in the UK, who, having been denied physical intervention for their adolescent child, obtain it in other countries; the ease with which young people denied such intervention can obtain information and medication via the internet, even paying for it by working in the sex trade; and, if the clinician decides to offer local care, the willingness of experienced clinicians in other countries to provide guidance.

MOTS CLÉS
Identité de genre ;
Rôle de genre ;
Transgenre ;
Évaluation psychologique ;
Intervention endocrinienne ;
Pédiatre

Résumé Bien que de nombreux cliniciens — peut-être sans le savoir — traitent de jeunes patients qui souffrent de troubles d'identité du genre, ils rencontrent rarement des cas où cet état soit profond et persistant. De fortes pressions sociales, au sein de la famille et à l'école, inhibent généralement toute tentative de révélation de tels troubles. Lorsque les familles identifient les troubles d'identité de genre et font appel à une aide médicale, une réponse prudente serait d'orienter le jeune vers un service pédiatrique spécialisé qui offre des soins multidisciplinaires, assurés par des professionnels expérimentés de santé mentale et des endocrinologues, en accord avec les standards internationaux de soins reconnus. Toutefois, dans de nombreux pays, de tels services n'existent pas, ou le service disponible a une approche qui n'est pas acceptée par les jeunes et leurs familles. Dans cette situation, le clinicien est confronté à une quantité de problèmes pratiques. Même les professionnels de santé mentale les plus confirmés ne peuvent pas prédire l'éventuelle persistance de l'état observé au stade prépubère. Au déclenchement de la puberté, il est souvent possible de poser un pronostic fiable. De nombreux pays avancés choisissent comme réponse clinique de suspendre la puberté. Cela soulage le stress causé par les changements corporels qui sont en conflit avec l'identité de genre de la jeune personne. De plus, les patients et les cliniciens disposent de plus de temps pour confirmer le pronostic, à la suite duquel l'alignement du corps sur l'identité de genre peut commencer. Initialement, cela est obtenu par l'administration d'hormones de conversion sexuelle. Enfin, généralement à l'âge adulte, il est possible de recourir à la chirurgie pour terminer la transformation physique. Le clinicien qui envisage un tel parcours de traitement pour un adolescent doit être au fait des points suivants : les questions juridiques et éthiques liées aux soins médicaux pour ce groupe de patients ; les besoins courants dans le domaine de l'éducation et de soutien pour la famille de la jeune personne et pour l'établissement scolaire ; l'entêtement de certains parents, notamment en Grande-Bretagne, qui s'étant vus refusé une intervention physique pour leur enfant adolescent vont l'obtenir dans d'autres pays ; la facilité avec laquelle des adolescents à qui l'on a refusé une intervention trouvent des informations et des traitements médicamenteux via Internet, qu'ils payent parfois par le biais de la prostitution ; et, si le clinicien décide de proposer des soins locaux, la disposition des cliniciens expérimentés dans d'autres pays à fournir des conseils.

PALABRAS CLAVE
Identidad de género;
Papel de género;
Transgénero;
Evaluación psicológica;
Intervención endocriniana;
Pediatra

Resumen A pesar de que muchos médicos, quizás incluso sin saberlo, tratan a jóvenes pacientes que sufren de trastornos de identidad de género importantes, es raro que se vean enfrentados a un caso en el que este estado parece grave y persistente. Existen fuertes presiones sociales, en la familia y en la escuela, que inhiben generalmente todo intento de revelar estos trastornos. Cuando las familias identifican este tipo de trastornos de identidad y recurren a una asistencia médica, la respuesta prudente debería consistir en orientar al joven hacia un servicio pediátrico especializado que ofrece cuidados multidisciplinares garantizados por profesionales expertos en salud mental y endocrinólogos, conformes a las normas internacionales reconocidas. Sin embargo, en numerosos países, este tipo de servicios no existe o bien el servicio disponible tiene un enfoque que los jóvenes o sus familias no aceptan. Ante esta situación, el médico se enfrenta a una serie de problemas prácticos. Incluso los profesionales de salud mental más experimentados no pueden prever la persistencia del estado observado en la fase anterior a la pubertad. Al inicio de la pubertad, a menudo es posible establecer un pronóstico fiable. La respuesta clínica de muchos países avanzados consiste en interrumpir la pubertad, lo cual alivia el estrés provocado por los cambios corporales que están en conflicto con la identidad

de género del/de la joven. Además, de este modo, tanto pacientes como médicos disponen de más tiempo para corroborar el pronóstico, tras lo cual puede empezar el trabajo de adaptación del cuerpo a la identidad de género. Inicialmente, se suministran hormonas de conversión sexual. Una vez que la persona ha alcanzado la edad adulta, es posible recurrir a la cirugía para terminar la transformación física. El médico que contemple un tratamiento de este tipo para un adolescente debe tener en cuenta una serie de parámetros: las cuestions jurídicas y éticas vinculadas con los cuidados médicos para este grupo de pacientes; las necesidades corrientes en el campo educativo y de apoyo a las familias y los colegios de los jóvenes; el empecinamiento de algunos padres, sobre todo en Gran Bretaña, a quienes se rechaza una intervención física para su hijo adolescente y que viajan a otro país para obtenerla; la facilidad con la que algunos adolescentes a quienes se ha rechazado la intervención encuentran información y tratamientos médicos en Internet y que a veces pagan protituyéndose. Finalmente, si el médico decide proponer cuidados locales, debe saber que existen médicos experimentados en otros países dispuestos a brindar su ayuda.

French abridged version

Le comportement transsexuel n'est pas rare chez les enfants prépubères et peut apparaître dès l'âge de deux ans (Cohen-Kettenis et Pfäfflin, 2003a). Chez 80 à 95 % de ces enfants, il disparaît à l'adolescence (Cohen-Kettenis et al., 2008) en évoluant généralement vers l'homosexualité ou la bisexualité (Zucker, 2005). Toutefois, la plupart de ceux qui à l'adolescence souffrent d'inconfort avec leur genre, continuent à vivre des troubles de l'identité de genre sévères à l'âge adulte (Wren, 2000 ; Cohen-Kettenis et Pfäfflin, 2003b ; Zucker, 2006).

Les expressions de transsexualité à l'adolescence sont moins prévalentes que chez les jeunes enfants, peut-être parce que les premiers sont plus conscients des pressions subies pour se conformer aux stéréotypes de genre. Donc, bien que la grande majorité des transsexuels adultes déclarent avoir vécu des désagréments dès les premières années (Green, 1999), la plupart ne demandent des soins médicaux que lorsqu'ils sont adultes. En Grande-Bretagne, en une année, on compte environ 1000 nouveaux cas « adultes » pour seulement 64 adolescents.

On peut donc en déduire que la plupart des parents d'enfants qui ont des troubles du genre ne demandent pas l'aide de spécialistes. Certains enfants peuvent réussir à cacher leurs sentiments ; certains parents peuvent ne pas considérer les variations de genre comme un problème ; d'autres peuvent choisir de les ignorer ; certains peuvent tenter de faire appliquer une conformité de genre en gratifiant un comportement qu'ils considèrent approprié et en punissant un comportement transgenre — approche encore recommandée par quelques médecins.

Les jeunes transgenres rejetés par leur famille risquent de recourir à la prostitution comme moyen de survie et d'obtention d'hormones (Holman et Goldberg, 2006). Ces mêmes enfants souffrent de brimades à l'école ; une étude portant sur 872 sujets transgenres révèle que plus de la moitié ont subi des brimades physiques et même des agressions sexuelles (Whittle et al., 2007). Dans le service de l'hôpital de Londres, 23 % des enfants de moins de 12 ans admettent avoir commis des actes d'automutilation (Di Ceglie et al., 2002) ; certains deviennent suicidaires, surtout au cours de la puberté lorsque les caractéristiques sexuelles non souhaitées deviennent plus prononcées. Les changements qui interviennent à la puberté entraînent souvent des inconvénients persistant le reste de la vie, et il devient donc impossible de « passer » pour une personne du sexe opposé. Des caractéristiques telles qu'une voix grave et une pilosité faciale et corporelle chez les jeunes filles « trans », ainsi que les seins chez les garçons « trans » conduisent à des interventions coûteuses et invasives à l'âge adulte.

La répugnance causée par le développement pubertaire phénotypique est une indication significative de la persistance de l'état. Toutefois, on ne dispose d'aucun test physique permettant de confirmer le diagnostic (Cohen-Kettenis et al., 2008). Il faut donc effectuer un *screening* méticuleux (Cohen-Kettenis, 2005) basé sur les propos des jeunes personnes elles-mêmes, sur les informations fournies par les parents et sur les tests psychologiques (Cohen-Kettenis et Pfäfflin, 2003d). On peut également se référer au Diagnostic and Statistical Manual (*manuel diagnostic et statistique des troubles mentaux*) (DSM-IV, American Psychiatric Association, 1994).

Chez les jeunes sujets soigneusement sélectionnés, il est possible de suspendre le développement pubertaire indésirable par le biais d'une intervention réversible et l'administration au début de la puberté d'inhibiteurs d'hormones qui bloquent la libération de gonadotrophines des glandes hypophysaire (Houk et Lee, 2006 ; Delemarre-van de Waal et Cohen-Kettenis, 2006). Cette méthode soulage le stress des jeunes sujets qui disposent de temps pour déterminer s'ils souhaitent devenir un homme ou une femme à l'âge adulte. La taille peut également être ajustée pour correspondre aux fourchettes de taille typiques d'hommes et de femmes (Cohen-Kettenis et al., 2008). Il est important de suivre les sujets pour surveiller la densité osseuse et la croissance harmonieuse et proportionnée du tronc et des jambes.

La puberté phénotypique reprend si l'on interrompt les inhibiteurs hormonaux ; il faut toutefois noter qu'aucun des jeunes sujets traités par les médecins néerlandais n'ont souhaité arrêter le traitement. Les protocoles néerlandais ne font mention d'aucun effet indésirable physique ou

psychologique (Delemarre-van de Waal et Cohen-Kettenis, 2006).

Les médecins britanniques ne proposent pas de suspension précoce de la puberté car selon eux l'exposition du cerveau aux effets complets d'hormones pubertaires endogènes peut conduire à la conformité de l'identité de genre. Il faut toutefois noter qu'aucune preuve ne vient étayer cet argument (Cohen-Kettenis et al., 2008) et qu'entretemps les jeunes « trans » peuvent vivre une détresse insupportable. Certains de ces jeunes britanniques se sont rendus aux États-Unis pour obtenir un traitement d'inhibition hormonale (Pugh, 2008). Des recommandations internationales (WPATH, 2001) sont en faveur d'une intervention précoce et des centres d'excellente réputation en Europe, en Amérique du Nord et en Australie offrent ce type de traitement. L'hôpital pédiatrique de Boston et l'équipe néerlandaise d'Amsterdam apportent leur soutien aux professionnels de santé qui souhaitent développer une expertise dans ce domaine.

Les traitements hormonaux destinés à masculiniser ou féminiser le corps en opposition à son phénotype ne sont généralement pas proposés avant l'âge de 16 ans (WPATH, 2001) ; la chirurgie n'est généralement pas entreprise avant l'âge de 18 ans, lorsqu'il y a une bonne compréhension des limites corporelles et fonctionnelles (Holman et Goldberg, 2006).

Il est vital d'obtenir un consentement éclairé approprié à chaque étape de l'intervention même lorsque celles-ci sont réversibles. La jeune personne doit comprendre l'impact potentiel du traitement sur la fertilité et, dans la plupart des circonstances, il sera nécessaire d'obtenir le consentement des parents ou des tuteurs (Zucker, 2007).

Tout échec de l'interruption du développement pubertaire complet en réponse à la demande d'un mineur compétent soulève des questions éthiques (Giordano, 2007).

Full English version

Introduction

Cross-gender behaviour in children may be apparent from age two years (Cohen-Kettenis and Pfäfflin, 2003a). In prepubertal children, it is not uncommon. Whereas, in adolescents, cross-gender expressions are far fewer (Cohen-Kettenis and Pfäfflin, 2003b).

It appears that most gender variant young people who are destined to be transsexual adults do not receive medical care for this condition. The great majority of adult transsexual people say they experienced the discomfort from the earliest years of life (Green, 1999). The National Health Service and private gender identity clinics in the UK receive about 1000 new ''adult'' cases per annum (personal communications with Dr Stuart Lorimer, Dr Kevan Wylie, Dr Susan Carr, Maria Morris and Dr Richard Curtis — May and June 2007). Yet, the UK's sole specialist treatment centre for ''children and adolescents'' in London received only 64 new referrals in the year to April 2008 (personal communication with Dr Domenico Di Ceglie — May 2008).

Family responses

It seems that most parents with gender variant children do not seek specialist help. Some will not regard gender variance as a problem. Others may be deeply stressed and try to ignore it. Some may try to persuade their child that the feelings are wrong or not acceptable; parents may reward typical gender behaviour and punish cross-gender behaviour. When families reject a gender variant adolescent, the sex trade may offer a means of survival (Holman and Goldberg, 2006).

Often, the family is unaware of their child's gender variance. Fear of bullying may inhibit a young person's expression of gender variance. A survey of 872 transgender people in 2006 showed that more than half had experienced bullying at school. This included physical abuse and even unwanted sexual behaviour (Whittle et al., 2007b). Also, young people may not reveal their gender feelings because they know that treatment is unavailable unless they travel abroad — for most, this is an unattainable ambition (Gendered Intelligence, 2007).

Families need to be aware of the risks that their gender variant children face as puberty approaches. In the London service, 23% of those aged 12 and over admitted to having engaged in self-harm (Di Ceglie et al., 2002). The actual number may be far greater. During puberty, those who identify as boys, despite their female bodies, find periods and breast development disgusting. They sometimes become frustrated by their small stature. Those who identify as girls, in rapidly developing male bodies, are equally distressed as their voices deepen, as they grow facial hair and prominent Adam's apples, as they experience erections and as they become taller than most other women. Some physical changes may be reversed but require painful and costly surgical procedures. Other changes are irreversible and cause life-long disadvantage, often making it impossible to ''pass'' as a person of the opposite sex, resulting in prejudice, harassment, humiliation and even violence (Whittle et al., 2007a).

Establishing a reliable prognosis

No physical test is available for detecting gender variance that is likely to develop into adult transsexualism (Cohen-Kettenis et al., 2008). Hence, clinicians must rely on the young person's own account of his or her feelings, on information from the parents about the way the child talks and behaves, and on psychological tests (Cohen-Kettenis and Pfäfflin, 2003d). These tests will be undertaken in the specialist centres that exist in some countries. Guidance on assessment is contained in the fourth edition of the *Diagnostic and Statistical Manual of Mental Disorders* (American Psychiatric Association, 1994). By adolescence, for the majority of both boys and girls (80—95%), the gender variance remits (Cohen-Kettenis et al., 2008). Prepubertal GID remits most frequently in adolescence and adulthood as homosexuality or bisexuality (Zucker, 2005). Whereas, in those who still experience gender discomfort in ''adolescence'', there is a very high rate of persistence of GID into adulthood (Wren, 2000; Zucker, 2006; Zucker and Cohen-Kettenis, 2008). The adolescent experiences

increasing disgust with phenotypic pubertal development, which is a significant indication that the condition will not remit. To provide a highly reliable prognosis, this is confirmed by careful psychological screening before any physical intervention is undertaken (Cohen-Kettenis, 2005).

Offering early suspension of puberty

In carefully screened young people, hormone-blockers that suppress the release of gonadotrophins from the pituitary, may be administered to suspend further unwanted pubertal development (Delemarre-Van de Waal and Cohen-Kettenis, 2006). This intervention relieves the young person's acute stress and provides more time for decisions to be made about whether to live as a man or as a woman in adulthood.

Treatment is monitored to ensure adequate bone development and mineralization, and proportionate growth of the trunk and the legs. In those with female phenotype who intend to live as men, suppression of endogenous oestrogen, combined with other medication, permits growth to continue so that a more typically male height may be achieved (Delemarre-Van de Waal and Cohen-Kettenis, 2006; Cohen-Kettenis et al., 2008) (limiting height in those with male phenotype is discussed below).

Clinicians who are reluctant to offer early suspension of puberty argue that, before a GID can be regarded as unremitting, the brain must have been exposed to the pubertal hormones that conform to the phenotype. There is, however, no evidence from brain research to support this argument (Cohen-Kettenis et al., 2008).

Upon cessation of hormone-blocking medication, phenotypic puberty would be resumed without harm to the young person. However, none of the patients treated by the Dutch clinicians has decided to stop the hormone-blocking intervention and none has regretted it (Delemarre-Van de Waal and Cohen-Kettenis, 2006).

Because early hormone-blocking medication is not available to young people in the UK, some have travelled to the USA (Pugh, 2008). Their families have borne the cost of evaluation and medications. The Children's Hospital, Boston has seen four such cases (personal communication with Dr Norman Spack — December 2007).

Changing gender role

There is no absolute rule about the right time to start living in the opposite gender role. However, for children who are clearly prepubertal, it is strongly recommended that the change of gender role is delayed because in so many the gender variance will remit. It is difficult to overcome the social impact of a change of gender role, especially in school (Cohen-Kettenis, 2005). Nonetheless, the gender variance in some children is so severe that they insist on changing gender role at a very young age.

Offering cross-sex hormones

Once the young person has made a firm decision to remain permanently in the new gender role, cross-sex hormone medication may be offered. This is administered in a gradually increasing dosage that is ultimately adequate to masculinise or feminise the body in opposition to the genotype/phenotype (Delemarre-Van de Waal and Cohen-Kettenis, 2006). However, it is not usually offered before age 16. In those with male phenotype who intend to live as women, oestrogens have the added benefit of restricting overall height so that it falls into the typical female range. The latter may be more beneficial if offered before age 16.

The Children's Hospital, Boston is mentoring clinicians elsewhere in the use of cross-sex hormones, as well as hormone blocking, once the young person has been assessed by an experienced mental health professional. The techniques involved are not complicated, the medication is well known in treating other paediatric conditions such as central precocious puberty and delayed puberty, and the follow-up protocols are relatively simple (personal communication with Dr Norman Spack — April 2008). The team in Amsterdam will also allow health professionals to visit and learn from their experience and expertise in this field.

Physical changes induced by cross-sex hormone medication are initiated slowly, but some are difficult or even impossible to reverse, including the effects on voice pitch and the growth of facial and body hair associated with masculinising hormones and, following feminising hormones, the development of breasts in those with male phenotype. Consequently, the decision to commence this medication is more critical than the previous decision to commence reversible hormone blocking medication.

Discussing gender confirmation surgery

Most gender variant adolescents seen by the specialised clinics have a straightforward wish for sex reassignment (Cohen-Kettenis and Pfäfflin, 2003c) and this may include surgery It is important to begin discussion of surgery at an early stage with any adolescents who express determination to transition so that they understand its limitations (Holman and Goldberg, 2006; Bowman and Goldberg, 2006).

The international standards of care published by the World Professional Association for Transgender Health (WPATH, 2001) state that any surgical intervention should not be carried out before the age of 18. Nonetheless, clinicians in Europe and North America need to be aware that it is possible, subject to stated safeguards, for a young person who is undergoing a male to female transition and aged at least 16, to obtain genital and gonadal surgery in Thailand, where one of the clinics states that it has a number of patients, from a variety of western countries, who underwent such surgery at age 16 (personal communication with Clinic Administrator— April 2008).

Informed consent

Properly informed consent to treatment is vital at each stage of intervention. In the UK, the young person must be competent to give informed consent to the physical interventions, even if, as with hormone blocking, they are entirely reversible. They must understand the risks and

benefits of treatment, and the consequences of not having treatment (Gillick, 1986). After the sixteenth birthday, a young person is automatically deemed to be competent (Family Law Reform Act, 1969). However, in most circumstances, the consent of parents (or others with Parental Responsibility) will be required as their support is a significant contributor to successful outcomes (Zucker, 2007).

Advising on fertility options

Before consenting to any physical treatment, young people should be carefully informed about the possibility of future infertility. They may not have contemplated being parents themselves. However, cross-sex hormones do, at least temporarily, negate their reproductive capabilities. The cessation of the medication would permit the restoration of their fertility, provided that only a few years had elapsed since its commencement. Cryopreservation of sperm and, possibly in the future, of ova, may maintain that capability (Spack, 2005). This might be undertaken before the start of or during a break from medication. For those whose gonads never developed beyond an early pubertal stage because of the early use of pubertal blocking drugs, it might require many years off all medications for sperm or ova to be retrieved. Ultimately, fertility will be lost. Unless there are further advances in reproductive medicine, surgery that involves the removal of gonads would result in the permanent loss of fertility.

Resolving ethical and legal issues

Clinicians may feel uncertain about treating gender variant young people because the evidence upon which treatment is based is incomplete (Zucker, 2005). However, no adverse long-term effects have yet emerged (Delemarre-Van de Waal and Cohen-Kettenis, 2006). International guidelines (WPATH, 2001) support early intervention and, in addition, a significant number of respected treatment centres, in Europe, North America and Australia, offer such treatment (Curtis et al., 2008). These factors would provide protection against a charge of negligence were any complaint made (Hurwitz, 2004).

The guidelines that specifically prohibit early suspension of puberty in the UK are under review (BSPED). The failure to provide treatment early enough to block full pubertal development in response to a competent minor's request, risks being unethical (Giordano, 2007).

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